

GOVERNOR'S PERMANENT ADVISORY COMMISSION ON TRAUMATIC BRAIN INJURIES

Meeting Date: January 16, 2014 8:30am @ BIARI, Cranston, RI

Attendance:

Kathleen Sherlock	Director Bandusky's designee RI Disability Law
Jennifer Andrade Koziol	Dept. of Health for Dr. Fine
Janice Hulme	Physical Therapist
Michael Baker	BIARI President
Sharon Brinkworth	BIARI, Executive Director
Heather Daglieri	Dept of BHDDH
Richard Muto	TBI Survivor
Colleen McCarthy	Post-Acute Rehab Facility Representative
Deborah Garneau	RI Department of Health
Linnea Tuttle	
Gina Albanese	

Excused: Leslie Mahler Cognitive Rehabilitation Specialist

Minutes for 12-19-13 were not voted on deferred to next meeting.

Discussion/Old/New Business:

1. **TBI Data – CDC and Registry:** Jen Andrade shared data from the CDC-Special Emphasis Report and information from the TBI Registry. Some points of discussion:
 - 2010 – almost 6000 TBI
 - 2011 – just under 6000 TBI
 - 2012 – 3000 TBI (entering data errors)
 - Why differences? TBI Registry – 1st or 2nd diagnosis only; hospital discharge information includes all diagnoses
 - Hospital D/C data is a couple of years behind because of how the numbers are put into the system (same for all departments)
 - Need for more timely information was addressed; we could advocate for this and cc. Dr. Sam Viner-Brown and Dr. Michael Fine
no date 1+ year; lag time for hospital data 1.5 years; possibly request special report from 2012.

Action: letter to be sent from commission to request more timely information
1st draft – Kate Sherlock; Janice Hulme

- Discussion regarding alternate ways that data can be entered more efficiently; question was raised as to whether we could use TBI funds, we are not able to do this.

One possibility suggested that we could go to legislation to advocate for positions at RI Department of Health; Richard suggested that maybe TBI survivors would be willing to enter data

- *It was decided that we would request data from DOH; if it is not resolved, we could include this in our annual report.*
- Discussion regarding process/timing of information – when info is sent to DOH and when they send letters to people who are injured (which then refers them to the BIARI); Hospitals are supposed to report within 2 weeks; system is not electronic; entries are manual

***Action:** Deb will get timing of when letters from DOH are sent from DOH to people who have been injured*

***Action:** Letter to DOH requesting 1) timely data, 2) dedicated staff, 3) electronic data collection, and 4) enforcement of 2 week submission policy for hospitals.*

2. **HAB Waiver:** Gina Albanese was asked to speak at next meeting regarding:
 - a. What is happening at PARI
 - b. What are the needs of the people served
 - c. Proposed changes to the HAB Waiver
 - d. Results from PARI survey
3. **Nursing Home Survey:** Richard reported on nursing home survey – need commissioners to look at the responses.

***Action:** Richard will send most recent copy to Kate who will forward it to the group; requesting commissioners to review and make changes and/or suggestions.*

4. **TBI Support Group:** Richard reported on support group meeting: 1) members would like to be involved with the commission, 2) Similar to the Domestic Violence production at Trinity, the play writer would like to do a play on TBI at Trinity, 3) someone in the group has ideas for workshops at the annual conference, 4) they added information to the continuum of care, 5) asked for number of people on BIARI mailing list (3000+), 6) Survey has been created to TBI survivors – will be sent out, 7) also survey to Community Mental Health Center
5. **Points of interest:**

Dr. Yin did not come to the meeting today, although interest has been expressed.
Richard heard of a Neuro-chiropractor practitioner

6. **TBI Fund:** Concern regarding TBI funds and possibility that funds will be lost: RFP has not been done; funds were not spent 2011-12 and also 2012-13; BIARI has been the only agency to get funding
- Kate handed out copies of statutes defining role of TBI Commission.
 - Need to request RFP process be continued as it has been, then next year we can ask for change and will review grants for TBI Committee.

***Action:** Kate will draft initial letter requesting RFP process to continue. Mike will help work on this. Letter to HSS Secretary Constantino; cc: Elena Nicolella, Michele Szylin, Robin Etchingham*

7. **Point of interest:** Neuro Restorative submitted a proposal for a new program, what is status?
8. **Meeting Dates:** It was decided that dates for 2014 meetings would be set for Thursdays 8:30 am, 3rd week of the month, until August. We will ask Leslie to do a meeting wizard to see if different dates /times would be better after that.
- February 20
 - March 20
 - April 17
 - May 15
 - June 19
 - July 17
 - August 21

***Action:** Meeting dates for 2014 Feb – Aug to be posted on Secretary of State website by Leslie. Leslie to set up meeting wizard to assess best meeting dates/times.*

9. **Focus Groups:** Kate asked if we could set up a subcommittee to work on getting input from different groups about gaps in continuum – to provide information about the GPACTBI and to ask “what are issues affecting you”, “we want to hear from you”. Need to have commissioners run focus groups within the community for 1) sports/youth injuries, 2) adults.

***Action:** Members to organize focus groups: Mike, Kate, Gina, Elizabeth (will also ask Kim about getting input from the VA)*

10. **Annual Report:** Need to work on an annual report to Governor and General Assembly; no date for going to the Governor; probably no legislation until next year. Report to be completed by the end of March and to include:
- What we have accomplished

- Reforms that are needed
- More funds needed (identify specific areas – HAB waiver, staffing DOH)
- Gaps identified
- What we need for data/information reporting
- Need to request a meeting with Senate President and House Speaker

***Action:** Draft of report to be completed by Mike, Janice, Sharon, Gina, Colleen, Richard to be presented at February 20 meeting.*

11. **TBI Grants:** Coming available, applications due March 7, 2014
12. **Announcement:** Sharon is retiring as of December, covering until new person is hired; this is her last GPAC TBI meeting as Director of BIARI.
13. **Commissioners – vacant position:** Need to identify a physiatrist for membership on the commission.
Action: Kate will attempt to contact Dr. Yin

Next meeting date & location: Thursday February 20, 2014 @ 8:30 am
Brain Injury Association of Rhode Island
935 Park Avenue, Suite #8
Cranston, RI 02910

Agenda for upcoming GPACTBI meeting 2-20-14

- Approve meeting minutes from 12-19-13 and 1-16-14
- Review letter from Connie Souza
- Updates on action items:
 - Letter to DOH – data reporting;
 - Info – timing of letters sent from DOH;
 - RFP draft letter;
 - Update from Focus Group Sub-Committee
 - Draft of Annual Report from Sub-Committee;
 - Update on Nursing Home Survey after member review
- Review attendance per bylaws
- Gina Albanese to report on HAB Waiver
- New business

Respectfully Submitted:
Janice Hulme
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1/30/14

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2014 Meeting Dates

All meetings at BIARI office
935 Park Avenue #8
Cranston, RI 02910
8:30 am – 10:00 am

February 20, 2014
March 20, 2014
April 17, 2014
May 15, 2014
June 19, 2014
July 17, 2014
August 21, 2014